

111TH CONGRESS
1ST SESSION

S. 819

To provide for enhanced treatment, support, services, and research for individuals with autism spectrum disorders and their families.

IN THE SENATE OF THE UNITED STATES

APRIL 2, 2009

Mr. DURBIN (for himself, Mr. CASEY, and Mr. MENENDEZ) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

A BILL

To provide for enhanced treatment, support, services, and research for individuals with autism spectrum disorders and their families.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE; TABLE OF CONTENTS.**

4 (a) SHORT TITLE.—This Act may be cited as the
5 “Autism Treatment Acceleration Act of 2009”.

6 (b) TABLE OF CONTENTS.—The table of contents for
7 this Act is as follows:

- Sec. 1. Short title; table of contents.
- Sec. 2. Findings.
- Sec. 3. Parental rights rule of construction.

Sec. 4. Definitions; technical amendment to the Public Health Service Act.

Sec. 5. Autism Care Centers Demonstration Project.

Sec. 6. Planning and demonstration grants for services for adults.

Sec. 7. National Registry.

Sec. 8. Multimedia campaign.

Sec. 9. Interdepartmental Autism Coordinating Committee.

Sec. 10. National Network for Autism Spectrum Disorders Research and Services.

Sec. 11. National training initiatives on autism spectrum disorders.

Sec. 12. Amendments relating to health insurance.

Sec. 13. Authorization of appropriations.

1 **SEC. 2. FINDINGS.**

2 Congress makes the following findings:

3 (1) Autism (sometimes called “classical au-
4 tism”) is the most common condition in a group of
5 developmental disorders known as autism spectrum
6 disorders.

7 (2) Autism spectrum disorders include autism
8 as well as Asperger syndrome, Retts syndrome,
9 childhood disintegrative disorder, and pervasive de-
10 velopmental disorder not otherwise specified (usually
11 referred to as PDD–NOS), as well as other related
12 developmental disorders.

13 (3) Individuals with autism spectrum disorders
14 have the same rights as other individuals to exert
15 control and choice over their own lives, to live inde-
16 pendently, and to participate fully in, and contribute
17 to, their communities and society through full inte-
18 gration and inclusion in the economic, political, so-
19 cial, cultural, and educational mainstream of society.

1 Individuals with autism spectrum disorders have the
2 right to a life with dignity and purpose.

3 (4) While there is no uniform prevalence or se-
4 verity of symptoms associated with autism spectrum
5 disorders, the National Institutes of Health has de-
6 termined that autism spectrum disorders are charac-
7 terized by 3 distinctive behaviors: impaired social
8 interaction, problems with verbal and nonverbal
9 communication, and unusual, repetitive, or severely
10 limited activities and interests.

11 (5) Both children and adults with autism spec-
12 trum disorders can show difficulties in verbal and
13 nonverbal communication, social interactions, and
14 sensory processing. Individuals with autism spec-
15 trum disorders exhibit different symptoms or behav-
16 iors, which may range from mild to significant, and
17 require varying degrees of support from friends,
18 families, service providers, and communities.

19 (6) Individuals with autism spectrum disorders
20 often need assistance in the areas of comprehensive
21 early intervention, health, recreation, job training,
22 employment, housing, transportation, and early, pri-
23 mary, and secondary education. With access to, and
24 assistance with, these types of services and supports,
25 individuals with autism spectrum disorders can live

1 rich, full, and productive lives. Greater coordination
2 and streamlining within the service delivery system
3 will enable individuals with autism spectrum dis-
4 orders and their families to access assistance from
5 all sectors throughout an individual's lifespan.

6 (7) A 2007 report from the Centers for Disease
7 Control and Prevention found that the prevalence of
8 autism spectrum disorders is estimated to be 1 in
9 150 people in the United States.

10 (8) The Harvard School of Public Health re-
11 ported that the cost of caring for and treating indi-
12 viduals with autism spectrum disorders in the
13 United States is more than \$35,000,000,000 annu-
14 ally (an estimated \$3,200,000 over an individual's
15 lifetime).

16 (9) Although the overall incidence of autism is
17 consistent around the globe, researchers with the
18 Journal of Paediatrics and Child Health have found
19 that males are 4 times more likely to develop an au-
20 tism spectrum disorder than females. Autism spec-
21 trum disorders know no racial, ethnic, or social
22 boundaries, nor differences in family income, life-
23 style, or educational levels, and can affect any child.

24 (10) Individuals with autism spectrum disorders
25 from low-income, rural, and minority communities

1 often face significant obstacles to accurate diagnosis
 2 and necessary specialized services, supports, and
 3 education.

4 (11) There is strong consensus within the re-
 5 search community that intensive treatment as soon
 6 as possible following diagnosis not only can reduce
 7 the cost of lifelong care by two-thirds, but also yields
 8 the most positive life outcomes for children with au-
 9 tism spectrum disorders.

10 (12) Individuals with autism spectrum disorders
 11 and their families experience a wide range of medical
 12 issues. Few common standards exist for the diag-
 13 nosis and management of many aspects of clinical
 14 care. Behavioral difficulties may be attributed to the
 15 overarching disorder rather than to the pain and dis-
 16 comfort of a medical condition, which may go unde-
 17 tected and untreated. The health care and other
 18 treatments available in different communities can
 19 vary widely. Many families, lacking access to com-
 20 prehensive and coordinated health care, must fend
 21 for themselves to find the best health care, treat-
 22 ments, and services in a complex clinical world.

23 (13) Effective health care, treatment, and serv-
 24 ices for individuals with autism spectrum disorders
 25 depends upon a continuous exchange among re-

1 searchers and caregivers. Evidence-based and prom-
2 ising autism practices should move quickly into com-
3 munities, allowing individuals with autism spectrum
4 disorders and their families to benefit from the new-
5 est research and enabling researchers to learn from
6 the life experiences of the people whom their work
7 most directly affects.

8 (14) There is a critical shortage of appro-
9 priately trained personnel across numerous impor-
10 tant disciplines who can assess, diagnose, treat, and
11 support children and adults with autism spectrum
12 disorders and their families. Practicing professionals,
13 as well as those in training to become professionals,
14 need the most up-to-date practices informed by the
15 most current research findings.

16 (15) The appropriate goals of the Nation re-
17 garding individuals with autism spectrum disorder
18 are the same as the appropriate goals of the Nation
19 regarding individuals with disabilities in general, as
20 established in the Americans with Disabilities Act of
21 1990 (42 U.S.C. 12101 et seq.): to assure equality
22 of opportunity, full participation, independent living,
23 and economic self-sufficiency for such individuals.

24 (16) Finally, individuals with autism spectrum
25 disorders are often denied health care benefits solely

1 because of their diagnosis, even though proven, ef-
 2 fective treatments for autism spectrum disorders do
 3 exist.

4 **SEC. 3. PARENTAL RIGHTS RULE OF CONSTRUCTION.**

5 Nothing in this Act shall be construed to modify the
 6 legal rights of parents or legal guardians under Federal,
 7 State, or local law regarding the care of their children.

8 **SEC. 4. DEFINITIONS; TECHNICAL AMENDMENT TO THE**
 9 **PUBLIC HEALTH SERVICE ACT.**

10 Part R of title III of the Public Health Service Act
 11 (42 U.S.C. 280i et seq.) is amended—

12 (1) by inserting after the header for part R the
 13 following:

14 **“Subpart 1—Surveillance and Research Program;**
 15 **Education, Early Detection, and Intervention;**
 16 **and Reporting”;**

17 (2) in section 399AA(d), by striking “part” and
 18 inserting “subpart”; and

19 (3) by adding at the end the following:

20 **“Subpart 2—Care for People With Autism Spectrum**
 21 **Disorders, Registry, and Public Education**

22 **“SEC. 399GG. DEFINITIONS.**

23 “Except as otherwise provided, in this subpart:

24 “(1) **AUTISM SPECTRUM DISORDER.**—The term
 25 ‘autism spectrum disorder’ means a developmental

1 disability that causes substantial impairments in the
 2 areas of social interaction, emotional regulation,
 3 communication, and the integration of higher-order
 4 cognitive processes and which may be characterized
 5 by the presence of unusual behaviors and interests.
 6 Such term includes autistic disorder, pervasive devel-
 7 opmental disorder (not otherwise specified),
 8 Asperger syndrome, Retts disorder, childhood dis-
 9 integrative disorder, and other related developmental
 10 disorders.

11 “(2) ADULT WITH AUTISM SPECTRUM DIS-
 12 ORDER.—The term ‘adult with autism spectrum dis-
 13 order’ means an individual with an autism spectrum
 14 disorder who has attained 22 years of age.

15 “(3) AFFECTED INDIVIDUAL.—The term ‘af-
 16 fected individual’ means an individual with an au-
 17 tism spectrum disorder.

18 “(4) AUTISM.—The term ‘autism’ means an au-
 19 tism spectrum disorder or a related developmental
 20 disability.

21 “(5) AUTISM MANAGEMENT TEAM.—The term
 22 ‘autism management team’ means a group of autism
 23 care providers, including behavioral specialists, phy-
 24 sicians, psychologists, social workers, family thera-
 25 pists, nurse practitioners, nurses, educators, other

1 appropriate personnel, and family members who
 2 work in a coordinated manner to treat individuals
 3 with autism spectrum disorders and their families.
 4 Such team shall determine the specific structure and
 5 operational model of its specific autism care center,
 6 taking into consideration cultural, regional, and geo-
 7 graphical factors.

8 “(6) CARE MANAGEMENT MODEL.—The term
 9 ‘care management model’ means a model of care
 10 that with respect to autism—

11 “(A) is centered on the relationship be-
 12 tween an individual with an autism spectrum
 13 disorder and his or her family and their per-
 14 sonal autism care coordinator;

15 “(B) provides services to individuals with
 16 autism spectrum disorders to improve the man-
 17 agement and coordination of care provided to
 18 patients and their families; and

19 “(C) has established, where practicable, ef-
 20 fective referral relationships between the autism
 21 care coordinator and the major medical, edu-
 22 cational, and behavioral specialties and ancillary
 23 services in the region.

24 “(7) CHILD WITH AUTISM SPECTRUM DIS-
 25 ORDER.—The term ‘child with autism spectrum dis-

1 order’ means an individual with an autism spectrum
2 disorder who has not attained 22 years of age.

3 “(8) INTERVENTIONS.—The term ‘interven-
4 tions’ means the educational methods and positive
5 behavioral support strategies designed to improve or
6 ameliorate symptoms associated with autism spec-
7 trum disorders.

8 “(9) NETWORK.—The term ‘Network’ means
9 the Network for Autism Spectrum Disorders Re-
10 search and Services described in section 10 of the
11 Autism Treatment Acceleration Act of 2009.

12 “(10) PERSONAL PRIMARY CARE COORDI-
13 NATOR.—The term ‘personal primary care coordi-
14 nator’ means a physician, nurse, nurse practitioner,
15 psychologist, social worker, family therapist, educa-
16 tor, or other appropriate personnel (as determined
17 by the Secretary) who has extensive expertise in
18 treatment and services for individuals with autism
19 spectrum disorders, who—

20 “(A) practices in an autism care center;
21 and

22 “(B) has been trained to coordinate and
23 manage comprehensive autism care for the
24 whole person.

1 “(11) PROJECT.—The term ‘project’ means the
2 autism care center demonstration project established
3 under section 399HH.

4 “(12) SERVICES.—The term ‘services’ means
5 services to assist individuals with autism spectrum
6 disorders to live more independently in their commu-
7 nities and to improve their quality of life.

8 “(13) TREATMENTS.—The term ‘treatments’
9 means the health services, including mental health
10 and behavioral therapy services, designed to improve
11 or ameliorate symptoms associated with autism spec-
12 trum disorders.

13 “(14) AUTISM CARE CENTER.—In this subpart,
14 the term ‘autism care center’ means a center that is
15 directed by a primary care coordinator who is an ex-
16 pert in autism spectrum disorder treatment and
17 practice and provides an array of medical, psycho-
18 logical, behavioral, educational, and family services
19 to individuals with autism and their families. Such
20 a center shall—

21 “(A) incorporate the attributes of the care
22 management model;

23 “(B) offer, through on-site service provi-
24 sion or through detailed referral and coordi-
25 nated care arrangements, an autism manage-

ment team of appropriate providers, including behavioral specialists, physicians, psychologists, social workers, family therapists, nurse practitioners, nurses, educators, and other appropriate personnel; and

“(C) have the capability to achieve improvements in the management and coordination of care for targeted beneficiaries.”.

SEC. 5. AUTISM CARE CENTERS DEMONSTRATION PROJECT.

Part R of title III of the Public Health Service Act (42 U.S.C. 280i), as amended by section 4, is further amended by adding at the end the following:

“SEC. 399HH. AUTISM CARE CENTER DEMONSTRATION PROJECT.

“(a) IN GENERAL.—Not later than 1 year after the date of enactment of the Autism Treatment Acceleration Act of 2009, the Secretary, acting through the Administrator of the Health Resources and Services Administration, shall establish a demonstration project for the implementation of an Autism Care Center Program (referred to in this section as the ‘Program’) to provide grants and other assistance to improve the effectiveness and efficiency in providing comprehensive care to individuals diagnosed with autism spectrum disorders and their families.

1 “(b) GOALS.—The Program shall be designed—

2 “(1) to increase—

3 “(A) comprehensive autism spectrum dis-
4 order care delivery;

5 “(B) access to appropriate health care
6 services, especially wellness and prevention care,
7 at times convenient for patients;

8 “(C) patient satisfaction;

9 “(D) communication among autism spec-
10 trum disorder health care providers,
11 behaviorists, educators, specialists, hospitals,
12 and other autism spectrum disorder care pro-
13 viders;

14 “(E) school placement and attendance;

15 “(F) successful transition to postsecondary
16 education, vocational or job training and place-
17 ment, and comprehensive adult services for in-
18 dividuals with autism spectrum disorders, focus-
19 ing in particular upon the transitional period
20 for individuals between the ages of 18 and 25;

21 “(G) the quality of health care services,
22 taking into account nationally developed stand-
23 ards and measures;

24 “(H) development, review, and promulga-
25 tion of common clinical standards and guide-

1 lines for medical care to individuals with autism
 2 spectrum disorders;

3 “(I) development of clinical research
 4 projects to support clinical findings in a search
 5 for recommended practices; and

6 “(J) the quality of life of individuals with
 7 autism spectrum disorders, including commu-
 8 nication abilities, social skills, community inte-
 9 gration, and employment and other related
 10 services; and

11 “(2) to decrease—

12 “(A) inappropriate emergency room utiliza-
 13 tion, which can be accomplished through initia-
 14 tives such as expanded hours of care;

15 “(B) avoidable hospitalizations;

16 “(C) the duplication of health care serv-
 17 ices;

18 “(D) the inconvenience of multiple provider
 19 locations;

20 “(E) health disparities and inequalities
 21 that individuals with autism spectrum disorders
 22 face; and

23 “(F) preventable and inappropriate in-
 24 volvement with the juvenile and criminal justice
 25 systems.

1 “(c) ELIGIBLE ENTITIES.—To be eligible to receive
2 assistance under the Program, an entity shall—

3 “(1) be a State or a public or private nonprofit
4 entity;

5 “(2) agree to establish and implement an au-
6 tism care center that—

7 “(A) enables targeted beneficiaries to des-
8 ignate a personal primary care coordinator in
9 such center to be their source of first contact
10 and to recommend comprehensive and coordi-
11 nated care for the whole of the individual;

12 “(B) provides for the establishment of a
13 coordination of care committee that is com-
14 posed of clinicians and practitioners trained in
15 and working in autism spectrum disorder inter-
16 vention;

17 “(C) establishes a network of physicians,
18 psychologists, family therapists, behavioral spe-
19 cialists, social workers, educators, and health
20 centers that have volunteered to participate as
21 consultants to patient-centered autism care cen-
22 ters to provide high-quality care, focusing on
23 autism spectrum disorder care, at the appro-
24 priate times and places and in a cost-effective
25 manner;

1 “(D) works in cooperation with hospitals,
2 local public health departments, and the net-
3 work of patient-centered autism care centers, to
4 coordinate and provide health care;

5 “(E) utilizes health information technology
6 to facilitate the provision and coordination of
7 health care by network participants; and

8 “(F) collaborates with other entities to fur-
9 ther the goals of the program, particularly by
10 collaborating with entities that provide transi-
11 tional adult services to individuals between the
12 ages of 18 and 25 with autism spectrum dis-
13 order, to ensure successful transition of such in-
14 dividuals to adulthood; and

15 “(3) submit to the Secretary an application, at
16 such time, in such manner, and containing such in-
17 formation as the Secretary may require, including—

18 “(A) a description of the treatments, inter-
19 ventions, or services that the eligible entity pro-
20 poses to provide under the Program;

21 “(B) a demonstration of the capacity of
22 the eligible entity to provide or establish such
23 treatments, interventions, and services within
24 such entity;

1 “(C) a demonstration of the capacity of
2 the eligible entity to monitor and evaluate the
3 outcomes of the treatments, interventions, and
4 services described in subparagraph (A);

5 “(D) estimates of the number of individ-
6 uals and families who will be served by the eli-
7 gible entity under the Program, including an es-
8 timate of the number of such individuals and
9 families in medically underserved areas;

10 “(E) a description of the ability of the eli-
11 gible entity to enter into partnerships with com-
12 munity-based or nonprofit providers of treat-
13 ments, interventions, and services, which may
14 include providers that act as advocates for indi-
15 viduals with autism spectrum disorders and
16 local governments that provide services for indi-
17 viduals with autism spectrum disorders at the
18 community level;

19 “(F) a description of the ways in which ac-
20 cess to such treatments and services may be
21 sustained following the Program period;

22 “(G) a description of the ways in which the
23 eligible entity plans to collaborate with other
24 entities to develop and sustain an effective pro-
25 tocol for successful transition from children’s

1 services to adult services for individuals with
 2 autism spectrum disorder, particularly for indi-
 3 viduals between the ages of 18 and 25; and

4 “(H) a description of the compliance of the
 5 eligible entity with the integration requirement
 6 provided under section 302 of the Americans
 7 with Disabilities Act of 1990 (42 U.S.C.
 8 12182).

9 “(d) GRANTS.—The Secretary shall award 3-year
 10 grants to eligible entities whose applications are approved
 11 under subsection (c). Such grants shall be used to—

12 “(1) carry out a program designed to meet the
 13 goals described in subsection (b) and the require-
 14 ments described in subsection (c); and

15 “(2) facilitate coordination with local commu-
 16 nities to be better prepared and positioned to under-
 17 stand and meet the needs of the communities served
 18 by autism care centers.

19 “(e) ADVISORY COUNCILS.—

20 “(1) IN GENERAL.—Each recipient of a grant
 21 under this section shall establish an autism care cen-
 22 ter advisory council, which shall advise the autism
 23 care center regarding policies, priorities, and serv-
 24 ices.

1 “(2) MEMBERSHIP.—Each recipient of a grant
 2 shall appoint members of the recipient’s advisory
 3 council, which shall include a variety of autism care
 4 center service providers, individuals from the public
 5 who are knowledgeable about autism spectrum dis-
 6 orders, individuals receiving services through the
 7 Program, and family members of such individuals.
 8 At least 60 percent of the membership shall be com-
 9 prised of individuals who have received, or are re-
 10 ceiving, services through the Program or who are
 11 family members of such individuals.

12 “(3) CHAIRPERSON.—The recipient of a grant
 13 shall appoint a chairperson to the advisory council of
 14 the recipient’s autism care center who shall be—

15 “(A) an individual with autism spectrum
 16 disorder who has received, or is receiving, serv-
 17 ices through the Program; or

18 “(B) a family member of such an indi-
 19 vidual.

20 “(f) EVALUATION.—The Secretary shall enter into a
 21 contract with an independent third-party organization
 22 with expertise in evaluation activities to conduct an eval-
 23 uation and, not later than 180 days after the conclusion
 24 of the 3-year grant program under this section, submit
 25 a report to the Secretary, which may include measures

1 such as whether and to what degree the treatments, inter-
 2 ventions, and services provided through the Program have
 3 resulted in improved health, educational, employment, and
 4 community integration outcomes for individuals with au-
 5 tism spectrum disorders, or other measures, as the Sec-
 6 retary determines appropriate.

7 “(g) ADMINISTRATIVE EXPENSES.—Of the amounts
 8 appropriated to carry out this section, the Secretary shall
 9 allocate not more than 7 percent for administrative ex-
 10 penses, including the expenses related to carrying out the
 11 evaluation described in subsection (f).

12 “(h) SUPPLEMENT NOT SUPPLANT.—Amounts pro-
 13 vided to an entity under this section shall be used to sup-
 14 plement, not supplant, amounts otherwise expended for
 15 existing treatments, interventions, and services for individ-
 16 uals with autism spectrum disorders.”.

17 **SEC. 6. PLANNING AND DEMONSTRATION GRANTS FOR**
 18 **SERVICES FOR ADULTS.**

19 Part R of title III of the Public Health Service Act
 20 (42 U.S.C. 280i), as amended by section 5, is further
 21 amended by adding at the end the following:

22 **“SEC. 399II. PLANNING AND DEMONSTRATION GRANT FOR**
 23 **SERVICES FOR ADULTS.**

24 “(a) IN GENERAL.—In order to enable selected eligi-
 25 ble entities to provide appropriate services to adults with

1 autism spectrum disorders, to enable such adults to be as
 2 independent as possible, the Secretary shall establish—

3 “(1) a one-time, single-year planning grant pro-
 4 gram for eligible entities; and

5 “(2) a multiyear service provision demonstra-
 6 tion grant program for selected eligible entities.

7 “(b) PURPOSE OF GRANTS.—Grants shall be award-
 8 ed to eligible entities to provide all or part of the funding
 9 needed to carry out programs that focus on critical aspects
 10 of adult life, such as—

11 “(1) postsecondary education, vocational train-
 12 ing, self-advocacy skills, and employment;

13 “(2) residential services and supports, housing,
 14 and transportation;

15 “(3) nutrition, health and wellness, recreational
 16 and social activities; and

17 “(4) personal safety and the needs of individ-
 18 uals with autism spectrum disorders who become in-
 19 volved with the criminal justice system.

20 “(c) ELIGIBLE ENTITY.—An eligible entity desiring
 21 to receive a grant under this section shall be a State or
 22 other public or private nonprofit organization, including
 23 an autism care center.

24 “(d) PLANNING GRANTS.—

1 “(1) IN GENERAL.—The Secretary shall award
2 one-time grants to eligible entities to support the
3 planning and development of initiatives that will ex-
4 pand and enhance service delivery systems for adults
5 with autism spectrum disorders.

6 “(2) APPLICATION.—In order to receive such a
7 grant, an eligible entity shall—

8 “(A) submit an application at such time
9 and containing such information as the Sec-
10 retary may require; and

11 “(B) demonstrate the ability to carry out
12 such planning grant in coordination with the
13 State Developmental Disabilities Council and
14 organizations representing or serving individ-
15 uals with autism spectrum disorders and their
16 families.

17 “(e) IMPLEMENTATION GRANTS.—

18 “(1) IN GENERAL.—The Secretary shall award
19 grants to eligible entities that have received a plan-
20 ning grant under subsection (d) to enable such enti-
21 ties to provide appropriate services to adults with
22 autism spectrum disorders.

23 “(2) APPLICATION.—In order to receive a grant
24 under paragraph (1), the eligible entity shall submit

1 an application at such time and containing such in-
2 formation as the Secretary may require, including—

3 “(A) the services that the eligible entity
4 proposes to provide and the expected outcomes
5 for adults with autism spectrum disorders who
6 receive such services;

7 “(B) the number of adults and families
8 who will be served by such grant, including an
9 estimate of the adults and families in under-
10 served areas who will be served by such grant;

11 “(C) the ways in which services will be co-
12 ordinated among both public and nonprofit pro-
13 viders of services for adults with disabilities, in-
14 cluding community-based services;

15 “(D) where applicable, the process through
16 which the eligible entity will distribute funds to
17 a range of community-based or nonprofit pro-
18 viders of services, including local governments,
19 and such entity’s capacity to provide such serv-
20 ices;

21 “(E) the process through which the eligible
22 entity will monitor and evaluate the outcome of
23 activities funded through the grant, including
24 the effect of the activities upon adults with au-

1 tism spectrum disorders who receive such serv-
2 ices;

3 “(F) the plans of the eligible entity to co-
4 ordinate and streamline transitions from youth
5 to adult services;

6 “(G) the process by which the eligible enti-
7 ty will ensure compliance with the integration
8 requirement provided under section 302 of the
9 Americans With Disabilities Act of 1990 (42
10 U.S.C. 12182); and

11 “(H) a description of how such services
12 may be sustained following the grant period.

13 “(f) EVALUATION.—The Secretary shall contract
14 with a third-party organization with expertise in evalua-
15 tion to evaluate such demonstration grant program and,
16 not later than 180 days after the conclusion of the grant
17 program under subsection (e), submit a report to the Sec-
18 retary. The evaluation and report may include an analysis
19 of whether and to what extent the services provided
20 through the grant program described in this section re-
21 sulted in improved health, education, employment, and
22 community integration outcomes for adults with autism
23 spectrum disorders, or other measures, as the Secretary
24 determines appropriate.

1 “(g) ADMINISTRATIVE EXPENSES.—Of the amounts
 2 appropriated to carry out this section, the Secretary shall
 3 set aside not more than 7 percent for administrative ex-
 4 penses, including the expenses related to carrying out the
 5 evaluation described in subsection (f).

6 “(h) SUPPLEMENT, NOT SUPPLANT.—Demonstra-
 7 tion grant funds provided under this section shall supple-
 8 ment, not supplant, existing treatments, interventions,
 9 and services for individuals with autism spectrum dis-
 10 orders.”.

11 **SEC. 7. NATIONAL REGISTRY.**

12 Part R of title III of the Public Health Service Act
 13 (42 U.S.C. 280i), as amended by section 6, is further
 14 amended by adding at the end the following:

15 **“SEC. 399JJ. NATIONAL REGISTRY FOR AUTISM SPECTRUM**
 16 **DISORDERS.**

17 “(a) ESTABLISHMENT.—The Secretary, in consulta-
 18 tion with national health organizations and professional
 19 societies with experience and expertise relating to autism
 20 spectrum disorders, shall establish a voluntary population-
 21 based registry of cases of autism spectrum disorders. Such
 22 registry shall be known as the ‘National Registry for Au-
 23 tism Spectrum Disorders’ (referred to in this section as
 24 the ‘Registry’). The Secretary shall ensure that the Reg-

1 istry maintains the privacy of individuals and the highest
2 level of medical and scientific research ethics.

3 “(b) PURPOSE.—The purpose of the Registry is to
4 facilitate the collection, analysis, and dissemination of
5 data related to autism spectrum disorders that can in-
6 crease understanding of causal factors, rates, and trends
7 of autism spectrum disorders.

8 “(c) ACTIVITIES.—In carrying out the Registry, the
9 Secretary may—

10 “(1) implement a surveillance and monitoring
11 system that is based on thorough and complete med-
12 ical diagnosis data, clinical history, and medical
13 findings;

14 “(2) collect standardized information con-
15 cerning the environmental, medical, social, and ge-
16 netic circumstances that may correlate with diag-
17 nosis of autism spectrum disorders;

18 “(3) promote the use of standardized autism
19 spectrum disorder investigation and reporting tools
20 of the Centers for Disease Control and Prevention,
21 as well as standardized autism spectrum disorder
22 protocols;

23 “(4) establish a standardized classification sys-
24 tem for defining subcategories of autism spectrum
25 disorders for surveillance research activities; and

1 “(5) support multidisciplinary reviews of autism
2 spectrum disorders.”.

3 **SEC. 8. MULTIMEDIA CAMPAIGN.**

4 Part R of title III of the Public Health Service Act
5 (42 U.S.C. 280i), as amended by section 7, is further
6 amended by adding at the end the following:

7 **“SEC. 399KK. MULTIMEDIA CAMPAIGN.**

8 “(a) IN GENERAL.—The Secretary, in order to en-
9 hance existing awareness campaigns and provide for the
10 implementation of new campaigns, shall award grants to
11 public and nonprofit private entities for the purpose of
12 carrying out multimedia campaigns to increase public edu-
13 cation and awareness and reduce stigma concerning—

14 “(1) healthy developmental milestones for in-
15 fants and children that may assist in the early iden-
16 tification of the signs and symptoms of autism spec-
17 trum disorders; and

18 “(2) autism spectrum disorders through the
19 lifespan and the challenges that individuals with au-
20 tism spectrum disorders face, which may include
21 transitioning into adulthood, securing appropriate
22 job training or postsecondary education, securing
23 and holding jobs, finding suitable housing, inter-
24 acting with the correctional system, increasing inde-
25 pendence, and attaining a good quality of life.

1 “(b) ELIGIBILITY.—To be eligible to receive a grant
2 under subsection (a), an entity shall—

3 “(1) submit to the Secretary an application at
4 such time, in such manner, and containing such in-
5 formation as the Secretary may require; and

6 “(2) provide assurance that the multimedia
7 campaign implemented under such grant will provide
8 information that is tailored to the intended audience,
9 which may be a diverse public audience or a specific
10 audience, such as health professionals, criminal jus-
11 tice professionals, or emergency response profes-
12 sionals.”.

13 **SEC. 9. INTERDEPARTMENTAL AUTISM COORDINATING**
14 **COMMITTEE.**

15 (a) ESTABLISHMENT.—There is established a com-
16 mittee, to be known as the “Interdepartmental Autism Co-
17 ordinating Committee” (referred to in this section as the
18 “Committee”), to coordinate all Federal efforts concerning
19 autism spectrum disorders.

20 (b) RESPONSIBILITIES.—In carrying out its duties
21 under this section, the Committee shall—

22 (1) develop and annually update a summary of
23 developments in research on autism spectrum dis-
24 orders, services for people on the autism spectrum

1 and their families, and programs that focus on peo-
2 ple on the autism spectrum;

3 (2) monitor governmental and nongovernmental
4 activities with respect to autism spectrum disorders;

5 (3) make recommendations to the Secretary of
6 Health and Human Services and other relevant
7 heads of agencies (referred to in this subsection as
8 the “agency heads”) regarding any appropriate
9 changes to such activities and any ethical consider-
10 ations relating to those activities;

11 (4) make recommendations to the agency heads
12 regarding public participation in decisions relating to
13 autism spectrum disorders;

14 (5) develop and annually update a strategic
15 plan, including proposed budgetary requirements, for
16 conducting and supporting research related to au-
17 tism spectrum disorders, services for individuals on
18 the autism spectrum and their families, and pro-
19 grams that focus on such individuals and their fami-
20 lies; and

21 (6) annually submit to Congress and the Presi-
22 dent such strategic plan and any updates to such
23 plan.

24 (c) MEMBERSHIP.—

1 (1) FEDERAL MEMBERS.—The Committee shall
2 be composed of—

3 (A) the Director of the National Institutes
4 of Health, and the directors of such national re-
5 search institutes of the National Institutes of
6 Health as the Director determines appropriate;

7 (B) the heads of other agencies within the
8 Department of Health and Human Services, as
9 the Secretary determines appropriate; and

10 (C) representatives of the Department of
11 Education, the Department of Defense, and
12 other Federal agencies that provide services to
13 individuals with autism spectrum disorders and
14 their families or that have programs that affect
15 individuals with autism spectrum disorders, as
16 the Secretary determines appropriate.

17 (2) NON-FEDERAL MEMBERS.—Not less than
18 $\frac{2}{5}$ of the total membership of the Committee shall
19 be composed of public members to be appointed by
20 the Secretary, of which—

21 (A) at least one such member shall be an
22 individual with an autism spectrum disorder;

23 (B) at least one such member shall be a
24 parent or legal guardian of an individual with
25 an autism spectrum disorder;

1 (C) at least one such member shall be a
2 representative of a nongovernmental organiza-
3 tion that provides services to individuals with
4 autism spectrum disorders or their families; and

5 (D) at least one such member shall be a
6 representative of a leading research, advocacy,
7 and service organization for individuals with au-
8 tism spectrum disorders and their families.

9 (d) ADMINISTRATIVE SUPPORT; TERMS OF SERVICE;
10 OTHER PROVISIONS.—The following provisions shall apply
11 with respect to the Committee:

12 (1) The Committee shall receive necessary and
13 appropriate administrative support from the Sec-
14 retary.

15 (2) Members of the Committee appointed under
16 subsection (c)(2) shall serve for a term of 4 years
17 and may be reappointed for one or more additional
18 4-year terms. The term of any member appointed
19 under subsection (c)(2)(C) or subsection (c)(2)(D)
20 shall expire if the member no longer represents the
21 organization described in such subsections. Any
22 member appointed to fill a vacancy for an unexpired
23 term shall be appointed for the remainder of such
24 term. A member may serve after the expiration of

1 the member's term until a successor has taken of-
 2 fice.

3 (3) The Committee shall be chaired by the Sec-
 4 retary or the Secretary's designee. The Committee
 5 shall meet at the call of the chairperson and not
 6 fewer than 2 times each year.

7 (4) All meetings of the Committee or its sub-
 8 committees shall be public and shall include appro-
 9 priate time periods for questions and presentations
 10 by the public.

11 (5) The Committee may convene workshops and
 12 conferences.

13 (e) SUBCOMMITTEES: ESTABLISHMENT AND MEM-
 14 BERSHIP.—

15 (1) ESTABLISHMENT OF SUBCOMMITTEES.—In
 16 carrying out its functions, the Committee may estab-
 17 lish—

18 (A) a subcommittee on research on autism
 19 spectrum disorders;

20 (B) a subcommittee on services for individ-
 21 uals with autism spectrum disorders and their
 22 families and programs that focus on individuals
 23 with autism spectrum disorders; and

24 (C) such other subcommittees as the Com-
 25 mittee determines appropriate.

1 (2) MEMBERSHIP.—Subcommittees may include
2 as members individuals who are not members of the
3 Committee.

4 (3) MEETINGS.—Subcommittees may hold such
5 meetings as are necessary.

6 (f) INTERAGENCY AUTISM COORDINATING COM-
7 MITTEE.—Part R of title III of the Public Health Service
8 Act (42 U.S.C. 280i) is amended by striking section
9 399CC (42 U.S.C. 284i–2).

10 **SEC. 10. NATIONAL NETWORK FOR AUTISM SPECTRUM DIS-**
11 **ORDERS RESEARCH AND SERVICES.**

12 (a) DEFINITIONS.—In this section:

13 (1) SERVICES.—The term “services” means
14 services to assist individuals with autism spectrum
15 disorders to live more independently in their commu-
16 nities and improve the quality of life of such individ-
17 uals.

18 (2) SECRETARY.—The term “Secretary” means
19 the Secretary of Health and Human Services.

20 (3) TREATMENTS.—The term “treatments”
21 means the health services, including mental health
22 and behavioral therapy services, designed to improve
23 or ameliorate symptoms associated with autism spec-
24 trum disorders.

1 (4) AUTISM CARE CENTER.—In this subpart,
2 the term “autism care center” means a center that
3 is directed by a primary care coordinator who is an
4 expert in autism spectrum disorder treatment and
5 practice and provides an array of medical, psycho-
6 logical, behavioral, educational, and family services
7 to individuals with autism and their families. Such
8 a center shall—

9 (A) incorporate the attributes of the care
10 management model;

11 (B) offer, through on-site service provision
12 or through detailed referral and coordinated
13 care arrangements, an autism management
14 team of appropriate providers, including behav-
15 ioral specialists, physicians, psychologists, social
16 workers, family therapists, nurse practitioners,
17 nurses, educators, and other appropriate per-
18 sonnel; and

19 (C) have the capability to achieve improve-
20 ments in the management and coordination of
21 care for targeted beneficiaries.

22 (b) ESTABLISHMENT OF THE NATIONAL NETWORK
23 FOR AUTISM SPECTRUM DISORDERS RESEARCH AND
24 SERVICES.—Not later than 1 year after the date of enact-
25 ment of this Act, the Secretary shall establish the National

1 Network for Autism Spectrum Disorders Research and
2 Services (referred to in this section as the “National Net-
3 work”). The National Network shall provide resources for,
4 and facilitate communication between, autism spectrum
5 disorder researchers and service providers for individuals
6 with autism spectrum disorders and their families.

7 (c) PURPOSES.—The purposes of the National Net-
8 work are to—

9 (1) build upon the infrastructure relating to au-
10 tism spectrum disorders that exists on the date of
11 enactment of this Act;

12 (2) strengthen linkages between autism spec-
13 trum disorders research and service initiatives at the
14 Federal, regional, State, and local levels;

15 (3) facilitate the translation of research on au-
16 tism spectrum disorders into services and treatments
17 to improve the quality of life for individuals with au-
18 tism and their families; and

19 (4) ensure the rapid dissemination of evidence-
20 based or promising autism spectrum disorder prac-
21 tices through the National Data Repository for Au-
22 tism Spectrum Disorders Research and Services de-
23 scribed in subsection (e).

24 (d) ORGANIZATION AND ACTIVITIES OF THE NA-
25 TIONAL NETWORK.—

1 (1) IN GENERAL.—In establishing the National
2 Network, the Secretary, acting through Adminis-
3 trator of the Health Resources and Services Admin-
4 istration, shall ensure that the National Network is
5 composed of entities at the Federal, regional, State,
6 and local levels.

7 (2) REGIONAL LEADERSHIP AND ORGANIZA-
8 TION.—In establishing the National Network, the
9 Secretary shall establish a Committee of Regional
10 Leaders, which shall ensure that regional participa-
11 tion is provided through the appointment of regional
12 leaders such as university- and community-based
13 partnerships that represent the needs and interests
14 of regional stakeholders (including individuals with
15 autism spectrum disorders and their families, pro-
16 viders, and researchers). The Committee of Regional
17 Leaders shall be responsible for monitoring, report-
18 ing, analyzing, and disseminating information in the
19 Data Repository described in subsection (e) to other
20 stakeholders to ensure that the information con-
21 tained in such Data Repository is widely available to
22 policymakers and service providers at the State and
23 local levels, and to facilitate communication between
24 various members of the National Network.

1 (3) STATE AND COMMUNITY LEVEL LEADER-
2 SHIP AND ORGANIZATION.—

3 (A) STATE DIRECTORS.—The regional
4 leaders appointed under paragraph (2) shall ap-
5 point State directors who shall coordinate the
6 activities of the National Network at the State
7 and community levels.

8 (B) STATE AND COMMUNITY SUBNET-
9 WORKS.—The Secretary shall ensure that the
10 State directors establish State and community
11 autism subnetworks, which shall engage in a va-
12 riety of frontline autism activities and provide
13 services, including comprehensive diagnostics,
14 treatment, resource and referral, and support
15 programs, for individuals with autism spectrum
16 disorders.

17 (e) NATIONAL DATA REPOSITORY FOR AUTISM
18 SPECTRUM DISORDERS RESEARCH AND SERVICES.—

19 (1) IN GENERAL.—The Secretary shall establish
20 a National Data Repository for Autism Spectrum
21 Disorders Research and Services (referred to in this
22 section as the “Data Repository”) and shall contract
23 with one eligible third-party entity to develop and
24 administer such repository (referred to in this sec-
25 tion as the “Data Repository Administrator”). The

1 Data Repository shall be used to collect, store, and
2 disseminate information regarding research, data,
3 findings, models of treatment, training modules, and
4 technical assistance materials related to autism spec-
5 trum disorders in order to facilitate the development
6 and rapid dissemination of research into best prac-
7 tices that improve care.

8 (2) ELIGIBILITY.—To be eligible to receive the
9 contract described in paragraph (1), an entity
10 shall—

11 (A) be a public or private nonprofit entity;

12 and

13 (B) have experience—

14 (i) collecting data;

15 (ii) developing systems to store data
16 in a secure manner that does not person-
17 ally identify individuals;

18 (iii) developing internet web portals
19 and other means of communicating with a
20 wide audience; and

21 (iv) making information available to
22 the public.

23 (3) CONTENTS.—The Data Repository shall in-
24 clude—

1 (A) emerging research, data, and findings
 2 regarding autism spectrum disorders from basic
 3 and applied researchers and service providers;

4 (B) emerging or promising models of treat-
 5 ment, service provision, and training related to
 6 autism spectrum disorders that are developed in
 7 individual care centers or programs; and

8 (C) training modules and technical assist-
 9 ance materials.

10 (4) DUTIES OF THE ADMINISTRATOR.—The
 11 Data Repository Administrator shall—

12 (A) collect information from autism spec-
 13 trum disorders research and service provision
 14 agencies and organizations including—

15 (i) Centers of Excellence in Autism
 16 Spectrum Disorder Epidemiology under
 17 section 399AA(b) of the Public Health
 18 Service Act (42 U.S.C. 280i(b));

19 (ii) autism care centers;

20 (iii) recipients of grants through the
 21 grant program for adult services under
 22 section 399II of the Public Health Service
 23 Act, as added by section 6 of this Act;

24 (iv) members and recipients of the na-
 25 tional training initiatives on autism spec-

1 trum disorders under section 399LL of the
2 Public Health Service Act, as added by
3 section 11 of this Act; and

4 (v) the Committee of Regional Lead-
5 ers, regional leaders, State directors, mem-
6 bers of State and community autism sub-
7 networks, and other entities, as determined
8 by the Secretary;

9 (B) securely store and maintain informa-
10 tion in the Data Repository in a manner that
11 does not personally identify individuals;

12 (C) make information in the Data Reposi-
13 tory accessible through an Internet web portal
14 or other appropriate means of sharing informa-
15 tion;

16 (D) ensure that the information contained
17 in the Data Repository is accessible to the Na-
18 tional Network, including health care providers,
19 educators, and other autism spectrum disorders
20 service providers at the national, State, and
21 local levels; and

22 (E) provide a means through the Internet
23 web portal, or through other means, for mem-
24 bers of the National Network to share informa-

1 tion, research, and best practices on autism
2 spectrum disorders.

3 (f) SUPPLEMENT NOT SUPPLANT.—Amounts pro-
4 vided under this section shall be used to supplement, not
5 supplant, amounts otherwise expended for existing net-
6 work or organizational structures relating to autism spec-
7 trum disorders.

8 **SEC. 11. NATIONAL TRAINING INITIATIVES ON AUTISM**
9 **SPECTRUM DISORDERS.**

10 Part R of title III of the Public Health Service Act
11 (42 U.S.C. 280i), as amended by section 8, is further
12 amended by adding at the end the following:

13 **“SEC. 399LL. NATIONAL TRAINING INITIATIVES ON AUTISM**
14 **SPECTRUM DISORDERS.**

15 “(a) NATIONAL TRAINING INITIATIVE SUPPLE-
16 MENTAL GRANTS.—

17 “(1) IN GENERAL.—The Secretary shall award
18 multiyear national training initiative supplemental
19 grants to eligible entities so that such entities may
20 provide training and technical assistance and to dis-
21 seminate information, in order to enable such enti-
22 ties to address the unmet needs of individuals with
23 autism spectrum disorders and their families.

24 “(2) ELIGIBLE ENTITY.—To be eligible to re-
25 ceive assistance under this section an entity shall—

1 “(A) be a public or private nonprofit enti-
2 ty, including University Centers for Excellence
3 in Developmental Disabilities and other service,
4 training, and academic entities; and

5 “(B) submit an application as described in
6 paragraph (3).

7 “(3) REQUIREMENTS.—An eligible entity that
8 desires to receive a grant under this paragraph shall
9 submit to the Secretary an application containing
10 such agreements and information as the Secretary
11 may require, including agreements that the training
12 program shall—

13 “(A) provide trainees with an appropriate
14 balance of interdisciplinary academic and com-
15 munity-based experiences;

16 “(B) have a demonstrated capacity to in-
17 clude individuals with autism spectrum dis-
18 orders, parents, and family members as part of
19 the training program to ensure that a person
20 and family-centered approach is used;

21 “(C) provide to the Secretary, in the man-
22 ner prescribed by the Secretary, data regarding
23 the outcomes of the provision of training and
24 technical assistance;

1 “(D) demonstrate a capacity to share and
 2 disseminate materials and practices that are de-
 3 veloped and evaluated to be effective in the pro-
 4 vision of training and technical assistance; and

5 “(E) provide assurances that training,
 6 technical assistance, and information dissemina-
 7 tion performed under grants made pursuant to
 8 this paragraph shall be consistent with the
 9 goals established under already existing dis-
 10 ability programs authorized under Federal law
 11 and conducted in coordination with other rel-
 12 evant State agencies and service providers.

13 “(4) ACTIVITIES.—An entity that receives a
 14 grant under this section shall expand and develop
 15 interdisciplinary training and continuing education
 16 initiatives for health, allied health, and educational
 17 professionals by engaging in the following activities:

18 “(A) Promoting and engaging in training
 19 for health, allied health, and educational profes-
 20 sionals to identify, diagnose, and develop inter-
 21 ventions for individuals with, or at risk of devel-
 22 oping, autism spectrum disorders.

23 “(B) Working to expand the availability of
 24 training and information regarding effective,
 25 lifelong interventions, educational services, and

1 community supports, including specific training
2 for criminal justice system, emergency health
3 care, legal, and other mainstream first re-
4 sponder professionals, to identify characteristics
5 of individuals with autism spectrum disorders
6 and to develop appropriate responses and inter-
7 ventions.

8 “(C) Providing technical assistance in col-
9 laboration with relevant State, regional, or na-
10 tional agencies, institutions of higher education,
11 advocacy groups for individuals with autism
12 spectrum disorders and their families, or com-
13 munity-based service providers.

14 “(D) Developing mechanisms to provide
15 training and technical assistance, including for-
16 credit courses, intensive summer institutes, con-
17 tinuing education programs, distance-based pro-
18 grams, and web-based information dissemina-
19 tion strategies.

20 “(E) Collecting data on the outcomes of
21 training and technical assistance programs to
22 meet statewide needs for the expansion of serv-
23 ices to children with autism spectrum disorders
24 and adults with autism spectrum disorders.

1 “(b) TECHNICAL ASSISTANCE.—The Secretary shall
2 reserve 2 percent of the appropriated funds to make a
3 grant to a national organization with demonstrated capac-
4 ity for providing training and technical assistance to the
5 entities receiving grants under subsection (a) to enable
6 such entities to—

7 “(1) assist in national dissemination of specific
8 information, including evidence-based and promising
9 best practices, from interdisciplinary training pro-
10 grams, and when appropriate, other entities whose
11 findings would inform the work performed by enti-
12 ties awarded grants;

13 “(2) compile and disseminate strategies and
14 materials that prove to be effective in the provision
15 of training and technical assistance so that the en-
16 tire network can benefit from the models, materials,
17 and practices developed in individual centers;

18 “(3) assist in the coordination of activities of
19 grantees under this section;

20 “(4) develop an Internet web portal that will
21 provide linkages to each of the individual training
22 initiatives and provide access to training modules,
23 promising training, and technical assistance prac-
24 tices and other materials developed by grantees;

1 “(5) convene experts from multiple interdiscipli-
 2 nary training programs and individuals with autism
 3 spectrum disorders and their families to discuss and
 4 make recommendations with regard to training
 5 issues related to the assessment, diagnosis of, treat-
 6 ment, interventions and services for, children with
 7 autism spectrum disorders and adults with autism
 8 spectrum disorders; and

9 “(6) undertake any other functions that the
 10 Secretary determines to be appropriate.

11 “(c) SUPPLEMENT NOT SUPPLANT.—Amounts pro-
 12 vided under this section shall be used to supplement, not
 13 supplant, amounts otherwise expended for existing net-
 14 work or organizational structures.”.

15 **SEC. 12. AMENDMENTS RELATING TO HEALTH INSURANCE.**

16 (a) ERISA.—

17 (1) IN GENERAL.—Subpart B of part 7 of sub-
 18 title B of title I of the Employee Retirement Income
 19 Security Act of 1974 (29 U.S.C. 1185 et seq.) is
 20 amended by adding at the end the following:

21 **“SEC. 715. REQUIRED COVERAGE FOR AUTISM SPECTRUM**
 22 **DISORDERS.**

23 “(a) IN GENERAL.—A group health plan, and a
 24 health insurance issuer providing health insurance cov-
 25 erage in connection with a group health plan, shall provide

1 coverage for the diagnosis of autism spectrum disorders
2 and the treatment of autism spectrum disorders.

3 “(b) RULE OF CONSTRUCTION.—Nothing in this sec-
4 tion shall be construed—

5 “(1) as preventing a group health plan or
6 health insurance issuer from imposing financial re-
7 quirements or limits in relation to benefits for the
8 diagnosis and treatment of autism spectrum dis-
9 orders, except that such financial requirements or
10 limits for any such benefits may not be less favor-
11 able to the individual than such financial require-
12 ments or limits for substantially all other medical
13 and surgical benefits covered by the plan, and there
14 shall be no separate financial requirements or limits
15 that are applicable only with respect to benefits for
16 the diagnosis or treatment of autism spectrum dis-
17 orders; and

18 “(2) to prevent a group health plan or a health
19 insurance issuer from negotiating the level and type
20 of reimbursement with a provider for care provided
21 in accordance with this section.

22 “(c) NOTICE UNDER GROUP HEALTH PLAN.—The
23 imposition of the requirements of this section shall be
24 treated as a material modification in the terms of the plan
25 described in section 102(a)(1), for purposes of assuring

1 notice of such requirements under the plan, except that
 2 the summary description required to be provided under the
 3 last sentence of section 104(b)(1) with respect to such
 4 modification shall be provided not later than the earlier
 5 of—

6 “(1) 60 days after the first day of the first plan
 7 year in which such requirements apply; or

8 “(2) in the first mailing after the date of enact-
 9 ment of the Autism Treatment Acceleration Act of
 10 2009 made by the plan or issuer to the participant
 11 or beneficiary.

12 “(d) PROHIBITIONS.—A group health plan, and a
 13 health insurance issuer offering group health insurance
 14 coverage in connection with a group health plan, shall
 15 not—

16 “(1) deny to an individual eligibility, or contin-
 17 ued eligibility, to enroll or to renew coverage under
 18 the terms of the plan, solely for the purpose of
 19 avoiding the requirements of this section; or

20 “(2) deny coverage otherwise available under
 21 this section on the basis that such coverage will
 22 not—

23 “(A) develop skills or functioning;

24 “(B) maintain skills or functioning;

25 “(C) restore skills or functioning; or

1 “(D) prevent the loss of skills or func-
2 tioning.

3 “(e) PREEMPTION; RELATION TO STATE LAW.—

4 “(1) IN GENERAL.—Nothing in this section
5 shall be construed to preempt any State law (or cost
6 sharing requirements under State law) with respect
7 to health insurance coverage that requires coverage
8 of at least the coverage for autism spectrum dis-
9 orders otherwise required under this section.

10 “(2) EFFECT ON OTHER LAWS.—Nothing in
11 this section shall be construed to affect or modify
12 the provisions of section 514 with respect to group
13 health plans.

14 “(f) DEFINITIONS.—In this section:

15 “(1) AUTISM SPECTRUM DISORDERS.—The
16 term ‘autism spectrum disorders’ means develop-
17 mental disabilities that cause substantial impair-
18 ments in the areas of social interaction, emotional
19 regulation, communication, and the integration of
20 higher-order cognitive processes and which may be
21 characterized by the presence of unusual behaviors
22 and interests. Such term includes autistic disorder,
23 pervasive developmental disorder (not otherwise
24 specified), Asperger syndrome, Retts disorder, and
25 childhood disintegrative disorder.

1 “(2) DIAGNOSIS OF AUTISM SPECTRUM DIS-
 2 ORDERS.—The term ‘diagnosis of autism spectrum
 3 disorders’ means medically necessary assessments,
 4 evaluations, or tests to diagnose whether an indi-
 5 vidual has an autism spectrum disorder.

6 “(3) TREATMENT OF AUTISM SPECTRUM DIS-
 7 ORDERS.—The term ‘treatment of autism spectrum
 8 disorders’ means the following care prescribed, pro-
 9 vided, or ordered for an individual diagnosed with an
 10 autism spectrum disorder by a physician, psycholo-
 11 gist, or other qualified professional who determines
 12 the care to be medically necessary:

13 “(A) Medications prescribed by a physician
 14 and any health-related services necessary to de-
 15 termine the need or effectiveness of the medica-
 16 tions.

17 “(B) Occupational therapy, physical ther-
 18 apy, and speech therapy.

19 “(C) Direct or consultative services pro-
 20 vided by a psychiatrist or psychologist.

21 “(D) Professional, counseling, and guid-
 22 ance services and treatment programs, includ-
 23 ing applied behavior analysis and other struc-
 24 tured behavioral programs. In this subpara-
 25 graph, the term ‘applied behavior analysis’

1 means the design, implementation and evalua-
 2 tion of environmental modifications, using be-
 3 havioral stimuli and consequences, to produce
 4 socially significant improvement in human be-
 5 havior, including the use of direct observation,
 6 measurement, and functional analysis of the re-
 7 lationship between environment and behavior.

8 “(E) Augmentative communication devices
 9 and other assistive technology devices.”.

10 (2) CLERICAL AMENDMENT.—The table of con-
 11 tents in section 1 of the Employee Retirement In-
 12 come Security Act of 1974 (29 U.S.C. 1001 note) is
 13 amended by inserting after the item relating to sec-
 14 tion 714 the following:

“Sec. 715. Required coverage for autism spectrum disorders.”.

15 (b) PUBLIC HEALTH SERVICE ACT.—

16 (1) GROUP MARKET.—Subpart 2 of part A of
 17 title XXVII of the Public Health Service Act (42
 18 U.S.C. 300gg–4 et seq.) is amended by adding at
 19 the end the following:

20 **“SEC. 2708. REQUIRED COVERAGE FOR AUTISM SPECTRUM**
 21 **DISORDERS.**

22 “(a) IN GENERAL.—A group health plan, and a
 23 health insurance issuer providing health insurance cov-
 24 erage in connection with a group health plan, shall provide

1 coverage for the diagnosis of autism spectrum disorders
2 and the treatment of autism spectrum disorders.

3 “(b) RULE OF CONSTRUCTION.—Nothing in this sec-
4 tion shall be construed—

5 “(1) as preventing a group health plan or
6 health insurance issuer from imposing financial re-
7 quirements or limits in relation to benefits for the
8 diagnosis and treatment of autism spectrum dis-
9 orders, except that such financial requirements or
10 limits for any such benefits may not be less favor-
11 able to the individual than such financial require-
12 ments or limits for substantially all other medical
13 and surgical benefits covered by the plan, and there
14 shall be no separate financial requirements or limits
15 that are applicable only with respect to benefits for
16 the diagnosis or treatment of autism spectrum dis-
17 orders; or

18 “(2) to prevent a group health plan or a health
19 insurance issuer from negotiating the level and type
20 of reimbursement with a provider for care provided
21 in accordance with this section.

22 “(c) NOTICE UNDER GROUP HEALTH PLAN.—The
23 imposition of the requirements of this section shall be
24 treated as a material modification in the terms of the plan
25 described in section 102(a)(1), for purposes of assuring

1 notice of such requirements under the plan, except that
 2 the summary description required to be provided under the
 3 last sentence of section 104(b)(1) with respect to such
 4 modification shall be provided not later than the earlier
 5 of—

6 “(1) 60 days after the first day of the first plan
 7 year in which such requirements apply; or

8 “(2) in the first mailing after the date of enact-
 9 ment of the Autism Treatment Acceleration Act of
 10 2009 made by the plan or issuer to the enrollee.

11 “(d) PROHIBITIONS.—A group health plan, and a
 12 health insurance issuer offering group health insurance
 13 coverage in connection with a group health plan, shall
 14 not—

15 “(1) deny to an individual eligibility, or contin-
 16 ued eligibility, to enroll or to renew coverage under
 17 the terms of the plan, solely for the purpose of
 18 avoiding the requirements of this section; or

19 “(2) deny coverage otherwise available under
 20 this section on the basis that such coverage will
 21 not—

22 “(A) develop skills or functioning;

23 “(B) maintain skills or functioning;

24 “(C) restore skills or functioning; or

1 “(D) prevent the loss of skills or func-
2 tioning.

3 “(e) PREEMPTION; RELATION TO STATE LAW.—

4 “(1) IN GENERAL.—Nothing in this section
5 shall be construed to preempt any State law (or cost
6 sharing requirements under State law) with respect
7 to health insurance coverage that requires coverage
8 of at least the coverage for autism spectrum dis-
9 orders otherwise required under this section.

10 “(2) ERISA.—Nothing in this section shall be
11 construed to affect or modify the provisions of sec-
12 tion 514 of the Employee Income Retirement Secu-
13 rity Act of 1974 with respect to group health plans.

14 “(f) DEFINITIONS.—In this section:

15 “(1) AUTISM SPECTRUM DISORDERS.—The
16 term ‘autism spectrum disorders’ means develop-
17 mental disabilities that cause substantial impair-
18 ments in the areas of social interaction, emotional
19 regulation, communication, and the integration of
20 higher-order cognitive processes and which may be
21 characterized by the presence of unusual behaviors
22 and interests. Such term includes autistic disorder,
23 pervasive developmental disorder (not otherwise
24 specified), and Asperger syndrome.

1 “(2) DIAGNOSIS OF AUTISM SPECTRUM DIS-
 2 ORDERS.—The term ‘diagnosis of autism spectrum
 3 disorders’ means medically necessary assessments,
 4 evaluations, or tests to diagnose whether an indi-
 5 vidual has an autism spectrum disorder.

6 “(3) TREATMENT OF AUTISM SPECTRUM DIS-
 7 ORDERS.—The term ‘treatment of autism spectrum
 8 disorders’ means the following care prescribed, pro-
 9 vided, or ordered for an individual diagnosed with an
 10 autism spectrum disorder by a physician, psycholo-
 11 gist, or other qualified professional who determines
 12 the care to be medically necessary:

13 “(A) Medications prescribed by a physician
 14 and any health-related services necessary to de-
 15 termine the need or effectiveness of the medica-
 16 tions.

17 “(B) Occupational therapy, physical ther-
 18 apy, and speech therapy.

19 “(C) Direct or consultative services pro-
 20 vided by a psychiatrist or psychologist.

21 “(D) Professional, counseling, and guid-
 22 ance services and treatment programs, includ-
 23 ing applied behavior analysis and other struc-
 24 tured behavioral programs. In this subpara-
 25 graph, the term ‘applied behavior analysis’

means the design, implementation and evaluation of environmental modifications, using behavioral stimuli and consequences, to produce socially significant improvement in human behavior, including the use of direct observation, measurement, and functional analysis of the relationship between environment and behavior.

“(E) Augmentative communication devices and other assistive technology devices.”.

(2) INDIVIDUAL MARKET.—Subpart 3 of part B of title XXVII of the Public Health Service Act (42 U.S.C. 300gg–51 et seq.) is amended by adding at the end the following:

“SEC. 2754. REQUIRED COVERAGE FOR AUTISM SPECTRUM DISORDERS.

“The provisions of section 2708 shall apply to health insurance coverage offered by a health insurance issuer in the individual market in the same manner as they apply to health insurance coverage offered by a health insurance issuer in connection with a group health plan in the small or large group market.”.

(c) EFFECTIVE DATES.—

(1) GROUP HEALTH PLANS.—

(A) IN GENERAL.—The amendment made by subsection (a) shall apply to group health

plans for plan years beginning on or after the date of enactment of this Act.

(B) SPECIAL RULE FOR COLLECTIVE BARGAINING AGREEMENTS.—In the case of a group health plan maintained pursuant to one or more collective bargaining agreements between employee representatives and one or more employers, any plan amendment made pursuant to a collective bargaining agreement relating to the plan which amends the plan solely to conform to any requirement added by the amendment made by subsections (a) and (b)(1) shall not be treated as a termination of such collective bargaining agreement.

(2) INDIVIDUAL PLANS.—The amendment made by subsection (b)(2) shall apply with respect to health insurance coverage offered, sold, issued, renewed, in effect, or operated in the individual market on or after the date of enactment of this Act.

SEC. 13. AUTHORIZATION OF APPROPRIATIONS.

There are authorized to be appropriated for fiscal years 2010 through 2014 such sums as may be necessary to carry out this Act.

